

N I C H D

National Institute
of Child Health and
Human Development

National Institutes of Health



Autism Research at the NICHD



For more information,
contact the NICHD at:

NICHD Clearinghouse

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The NICHD/NIDCD Network on the Neurobiology and Genetics of Autism: The Collaborative Programs of Excellence in Autism (CPEAs)

What is autism?

Autism is a complex biological disorder of development that lasts throughout a person's life. People with autism have problems with social interaction and communication, so they may have difficulty having a conversation with you, or they may not look you in the eye. They sometimes have behaviors that they *have* to do or that they do over and over, like not being able to listen until their pencils are lined up or saying the same sentence again and again. They may flap their arms to tell you they are happy, or they might hurt themselves to tell you they are not.

One person with autism may have different symptoms, show different behaviors, and come from different environments than other people with autism. Because of these differences, doctors now think of autism as a "spectrum" disorder, or a group of disorders with a range of similar features. Doctors classify people with autism spectrum disorder (ASD) based on their autistic symptoms. A person with mild autistic symptoms is at one end of the spectrum. A person with more serious symptoms of autism is at the other end of the spectrum. But they both have a form of ASD.

The National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health (NIH), is one of the NIH Institutes doing research into various aspects of autism, including its causes, how many people have it, and its treatments.

As part of these efforts, in 1997, the NICHD, in collaboration with the National Institute on Deafness and Other Communication Disorders (NIDCD), started a five-year, \$45 million, international Network on the Neurobiology and Genetics of Autism, comprised of 10 Collaborative Programs of Excellence in Autism (CPEA) to solve the mysteries of autism through research.

www.nichd.nih.gov

What is the CPEA Network?

The CPEA Network is the largest single research effort for autism to date. One of its tasks is to learn about the possible causes of autism, including genetic, immunological, and environmental causes. Each CPEA is also studying brain structure and brain function, and how autism changes as children grow and develop.

The Network has over 2,000 families of people with autism enrolled in research studies around the world. Following the lives of these families, scientists can learn how the condition changes as a person with autism gets older.

The CPEA also brings together scientists from more than 25 universities in the U.S., Canada, Britain, and five other countries. These experts come from different backgrounds and different countries, but they are united in trying to understand autism.

Who is in the CPEA Network?

To date, there are 10 CPEA sites around the country. Even though each site is studying a unique part of autism, diagnostic and other core information collected by CPEA sites in their studies are used to study research questions that no one project could address on its own. This joint research allows scientists to find similarities and differences among people with autism and their families. These research measures and methods will help future scientists do their own studies, to prove or disprove theories about autism. All of the CPEA sites work together on genetic studies of autism. The Network also participates in an International Consortium, and works with the Autism Genetic Research Exchange (AGRE) genetic repository. Each site also has a special focus of its own.

The CPEA sites include:

University of Washington

Seattle, WA

Doing studies about genes, brain function, and early diagnosis and regression in autism with the University of Alaska, University of Florida, University of Montana, University of Oregon, and Vanderbilt University. **Contact Dr. Cathy Brock 206-543-5153.**

University of Rochester

Rochester, NY

Doing animal and human studies of possible genetic and environmental mechanisms that may cause autism with York University, University of Toronto (Canada), Cornell Medical Center, and the USEPA. **Contact Dr. Patricia Rodier 716-275-2582.**

Albert Einstein

College of Medicine
Bronx, NY

Studying all aspects of hearing and sound processing in autism. **Contact Dr. Michelle Dunn 718-430-2130.**

Eunice Kennedy Shriver Center

Waltham, MA

Studying genetic neuroimaging and behavioral aspects of language and communication in autism with Boston University and Tufts New England Medical Center. **Contact Susan Bacalman 781-642-0211 or Helen Tager-Flusberg 617-414-1312.**

University of Utah

Salt Lake City, UT

Doing immunogenetic, neuroimaging, and neuropsychological studies of autism with Utah State University. **Contact Dr. William McMahon 801-585-7781.**

University of California, Los Angeles (UCLA)

Los Angeles, CA

Examining candidate genes, early diagnosis, and language and communication in autism. **Contact Dale Howard 310-825-0575.**

University of California at Irvine
Irvine, CA

Doing studies of candidate genes, brain structure, and regression in Autism Spectrum Disorder. **Contact Dr. Anne Spence 714-456-8848.**

University of Colorado Health Sciences Center

Denver, CO

Examining early diagnosis, movement, imitation, and sensory processing in autism and Fragile X with the University of Denver and Johns Hopkins University. **Contact Dr. Sally Rogers 303-315-6509.**

University of Pittsburgh

Pittsburgh, PA

Exploring autism as a disorder of information-processing, studying both strengths and weaknesses in autism with Carnegie Mellon University and Case Western Reserve University. **Contact Mrs. Evelyn Herbert 412-624-0818.**

Yale University

New Haven, CT

Doing studies about genes, brain function, and early diagnoses of autism and Asperger's Syndrome with the University of Chicago, University of California at Los Angeles, Oxford University (Britain), University of London (Britain), and an International Consortium, funded by the Medical Research Council of Great Britain and the Wellcome Fund. **Contact Kathleen Koenig, MSN 203-737-4337.**

How can I get involved with the CPEA Network?

For the CPEA Network to succeed in making breakthroughs in autism research, parents, children, and families need to help. The Network needs volunteers to take part in autism studies. There is no charge for any medical services that are provided as part of the research studies. Because of research requirements, you have to qualify for the CPEA studies, which means that you have certain qualities or features that fit into the research plan. If you qualify, you may join as many of the studies as you like, except for the genetic linkage studies. You may only enter one genetic linkage study. If you and your family qualify, you will receive free tests related to the specific study you join. Keep in mind that the Network does not currently give treatments for autism, but the CPEA sites are at some of the most advanced medical centers in the U.S., which do offer autism treatment for a fee.

If you are interested in getting involved with one of the CPEA studies, or want more information about one of the CPEA sites, contact the person listed on the centerfold map at the CPEA site nearest you.

For more information about the CPEA Network or about autism research at the NICHD, contact the NICHD Clearinghouse at:

Mail: PO Box 3006, Rockville, MD 20847
Phone: 1-800-370-2943
Fax: 301-984-1473
Email: NICHDClearinghouse@mail.nih.gov

The NICHD Autism Web Page, www.nichd.nih.gov/autism, also provides more information about autism research at the NICHD. You can comment on this or other *Autism Research at the NICHD* fact sheets through the Web site.

